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ABSTRACT

To study the psychological and social connotations of mental retardation in Canada, to identify demographic detail, and to develop research instruments and methodology, the proposed research studied the total population (110,000 persons) of Prince Edward Island. Subjects were randomly selected from ages 10 through 64. Prevalence tables are included, but the final results of the study are not yet available. The present knowledge is reviewed, and the methods to be used in the study are described. (JM)

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MENTAL RETARDATION IN A CANADIAN PROVINCE:

Elements of the Research Design

Report No. 1

C.W. Portal-Foster, Ph.D.

The Canadian Welfare Council
Research Branch
55 Parkdale Avenue
Ottawa 3, Ontario

July 1968

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This project is supported under Welfare Research Project 566-33-3, National Welfare Grants Program, Department of National Health and Welfare, Canada.

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U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
OFFICE OF EDUCATION

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MENTAL RETARDATION IN A CANADIAN PROVINCE

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PREFACE

This report has been prepared in reply to the numerous and continuing requests for copies of the original grant submission which was approved by the Department of National Health and Welfare in the spring of 1968. It closely follows the original document and omits any discussion of the progress of the study to date.

The original was, in effect, an application for a grant to conduct a feasibility study of the proposed project. The final report of this phase will be a more detailed research design for the major work, which it is anticipated will be initiated during 1969.

MENTAL RETARDATION IN A CANADIAN PROVINCE

INTRODUCTION

The effectiveness of planning and the projection of needs in any area of endeavour depends largely on the validity and reliability of available information. Conversely, planning carried out without adequate basic information often incurs extra and often heavy costs in both economic, and humanitarian terms. The field of mental retardation falls within this category, in that there is not enough basic information available for modern welfare planning. This is particularly evident in Canada and may be attributed to a wide range of factors, both historical and contemporary.

Not only has the accumulation of basic data on the incidence and prelevance of mental retardation been inadequate for social planning, but it has also been less extensive than in other areas of scientific interest and activity. Historically, retardates for whom primary concern was expressed included patients of various types of institutions although these groups constituted only a part of the total population of the mentally retarded. Studies were typically based upon hospital or clinic admission and case records, and were oriented primarily to bio-medical rather than socio-psychological purposes. These data presented a number of advantages to individuals conducting inquiries, but they also possessed a number of inherit dis-advantages.

Although they were inexpensive and readily available, they set severe limitations on data analysis procedures and were typically unsuitable for social and psychological investigations. Many medical researchers have commented upon the research limitations imposed by admission and case record data.

The present need for welfare planning in the field of mental retardation is the result primarily of technological and social change, advances in the medical treatment of retardation, and the promotional efforts of parents' groups. The rising expectations of and for the mentally retarded has precipitated their movement from major institution to home communities with a consequent increase in need for local services. In addition, retardates who would previously have been kept at home are taking advantage of more community services at an ever increasing rate.

The new dawn for the mentally retarded with its increased demand for valid basic data is a reflection of the improved understanding of the hitherto unknown potential of retardates to become more fully participating members of society. Its a symbol of an awakened national conscience.

This study is an attempt to provide valid data - the basic building blocks of sound social planning.

PURPOSE*

The purpose of the study is to facilitate the planning of services and programs for the mentally retarded through an increased understanding of the types, conditions and prevalence in Canada of their pathology.

Specifically, the purpose of the project will be to study mental retardation in a Canadian population in terms of:

1) psychological and social connotations;
2) distribution in the general population in relation to specified social and demographic factors, such as age, religion, sex and economic status.

The study will attempt to identify functional unities which have internal consistency and which will be reproducible on other populations by other researchers. It will determine the independence and interdependence of such unities and will evaluate the empirical effects of relatively homogeneous variables which appear as, but may not essentially represent, mental retardation.

A further purpose of the study is to develop research instruments and methodology which can have wide application within the North American Context.

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* The objectives and methodology of the project draw heavily on personal discussions of project staff with Dr. M.N. Beck, Director of Mental Health for Prince Edward Island, and Dr. Joseph R. Jastak, Director of the Delaware Study. In addition to these discussions, the writings of Beck, Jastak, Goodman, and the previous work of the project director have greatly influenced the direction of the project.

SIGNIFICANCE

There are numerous points of view about how and where the mentally retarded should receive care. There are strong advocates of, for example, major institutions, small community residences, or integrated schools. Other persons may favour physically separate schools, home adoption or 'villages' for the retarded or any of several other facilities and services. It appears that there is general agreement on only three major points: that much can be done for the mentally retarded, that facilities and services of whatever nature should be economically feasible while presenting maximal opportunities to the retarded and, finally, that there is insufficient information available upon which optimal planning can be based.

The significance of the study proposed here is that it will organize and report data related to the extent of need in an area that is typical of much of Canada. It will exploit a uniquely favourable research situation for the development of research instruments which will have application to other areas of the country. Finally, and perhaps more important, the study will lay the base of a theoretical construct relating needs in a defined Canadian population to necessary planning of facilities and services.

The necessity and scope of planning required in Canada for the mentally retarded is sobering in both its humanitarian and economic dimensions. For example, currently accepted

estimates place the mentally retarded population of Canada at approximately 600,000, which some 579,000 are living in non-institutional settings. From this large group come a disproportionate number of relief, charity, delinquent, criminal, and promiscuous persons,[1] though it is estimated that 525,000 of the Canadian retardates are capable of becoming either fully or partially self-supporting through vocational training or long-term employment in sheltered workshops.[2]

It is now well established that the social, psychological, intellectual, and economic aspects of mental retardation can be subjected to rigorous scientific investigation. However, the vital link between research findings and their application in the field rests largely upon a knowledge of the need for service - of whatever kind. The proposed major study is intended to form part of that important link.

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1 Portal-Foster, C.W., Aspects of Evaluation and Research in the Hamilton-Niagara Area, Toronto: Canadian Association for Retarded Children, 1966.

Charles, D.C., "Ability and Accomplishment of Persons Earlier Judged Mentally Deficient". Genet. Psychol. Monographs, Vol. 47: 3-71.

2 This estimate is based upon United States experience but there is no evidence that the Canadian situation is significantly different.

The Secretary's Committee on Mental Retardation, February 1962, Mental Retardation Program of the United States Department of Health, Education and Welfare (fiscal year 1964). Washington: U.S. Department of Health, Education and Welfare.

METHODOLOGY

The mentally retarded are often thought to display physiological pathologies ranging from epilepsy and hydrocephalus to blindness and mongolism.. Yet some of these individuals can function at or above what is accepted as the normal level. Cultural or environmental deprivation may nullify the superior intelligence of both children and adults. Persons from fine middle and upper-class homes may be functionally retarded due to psychological stresses caused by their economically superior circumstances.

The study is concerned with individuals who are functionally retarded, regardless of which condition or combination of conditions obtain.

1) Mental Retardation Defined: For purposes of the study mental retardation will be defined in psychometric and social terms. The definition takes cognizance of previous major studies of incidence and prevalence in order to facilitate comparative studies.*

2) The Population: The universe under study is the total population of Prince Edward Island. The Island is a separate political entity with a stable population of 110,000 and constitutes a feasible unit for study. The population is sufficiently heterogeneous in income, age, education and other factors to allow significant variations in prevalence of retardation to emerge.

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* Terms will be operationally defined in a subsequent report.

Osberg, Beck and others have reported on the unique characteristics of the Province for empirical research in mental retardation and mental health.[3] Established services for the mentally retarded are among the most advanced in North America. Upwards of 90 per cent of the trainable and non-trainable retarded have been studied by a child psychiatry team. Also, it is estimated that all trainable retardates are enrolled in day training class facilities.

Data which has been amassed for previous and on-going projects are available to Council researchers for validation purposes.

3) Sampling: Subjects for study will be selected at random from the total population aged 10 through 64.

4) Domicile Frame: A frame of all inhabited domiciles in the province will be constructed using data from existing sources. The study sample will be drawn from the domicile frame. Field checks will be carried out on the frame by actual on-the-spot observation in a number of areas selected on the basis of high probability of change. New housing developments would be included in the test area.

3

Beck, M.N., Prince Edward Island Home-Strengthening Services for the Retarded. Charlottetown: Department of Health, Division of Mental Health, 1967.

Beck, M.N., Outline of the Potential of Prince Edward Island for Psychiatric Research. Charlottetown: Department of Health, Division of Mental Health, 1964.

Osberg, James W., Opportunities for Operation Research: Prince Edward Island, Bethesda, Md.: Department of Health, Education, and Welfare. Public Health Service, (National Institute of Health), 1965.

5) Research Unit: The basic research unit will be 'households' defined as consisting of related family members in addition to unrelated persons such as lodgers, foster children, and wards.

6) Household Sample: A sample of 1,500 households is proposed for the study and will be selected at random from the domicile frame. The sample will be divided into a number of sub -samples to facilitate calculation of sampling errors and the replication of findings.

7) Screening Interviews: All persons in sample households will be administered a screening interview to identify retarded and non-retarded populations.

8) Sample Population: The sample population isolated by the screening instrument will be subjected to an intensive psychometric and social examination.*

9) Sampling of Non-Retarded Population: The non-retarded population as defined by the screening interview will be sampled for intensive interviewing. This procedure will provide a test of validity for the screening technique and provide a control group for analytical purposes.

10) Instrumentation: Instrumentation will consist of three schedules:

A) Domicile Frame

B) Interview Schedule: an intensive schedule with emphasis on psychometric and social measures.

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* Extensive physiological and psychiatric data on many subjects will be available from existing sources.

C) Screening Schedule: a lesser version of the intensive interview schedule.

Creation and refinement of instruments will be a major undertaking for the design phase of the study.

11) Field Tests: Field tests will be conducted to test the methodology, domicile frame, and interview schedules. Field tests will also serve as training experience for the researchers and will provide information upon which to base budget estimates for the larger study.

12) Data Analysis: Both descriptive and inferential statistics will be employed in the analysis of study data. Decisions regarding data analysis will depend upon the final form of instruments, requirements of the study area, and alternative available data on the sample population.

PRESENT STATE OF KNOWLEDGE

Previous Work by the Canadian Welfare Council

The Canadian Welfare Council and its predecessor, the Canadian Council on Child Welfare, has been engaged for many years in studies and other activities related to welfare services in many parts of the country.

Dr. Charlotte Whitton's 1931 study of Prince Edward Island dealt with available services in that province and found little to commend in care for the feeble minded. They were, according to the report, 'lumped' together and dealt with as one

heterogeneous mass - the only claim to commendation of such a system being its reputed economy. Studies carried out by the Council in other provinces used a similar approach - determination of need (or an approximation) followed by a comparison with existing services.[4]

During the intervening decades the Council, through its divisions and committees, has carried out a number of significant activities related to the need for child welfare services - on some occasions,services specifically for the mentally retarded. Notable were the Council's brief to the Federal-Provincial Conference on Mental Retardation, 1964, co-sponsorship of the Canadian Conference on Children, 1965, co-sponsorship of the current Canadian Commission on Emotional and Learning Disorders in Children, the forthcoming Comprehensive Statement on Social Policies for Canada, and a statement on abortion, which was presented to the House of Commons Standing Committee on Health and Welfare in February 1968.

The establishment of the Council's Research Branch early in this decade signalled a more scientific approach. A number of studies directly or indirectly related to mental retardation

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4 Whitton, Charlotte. Report of the New Brunswick Child Welfare Survey. Ottawa: Canadian Council on Child Welfare, 1929. Sponsored by a grant from the Kiwanis Club of Saint John City.

Whitton, Charlotte. Child Protection and Social Services in Prince Edward Island. Ottawa: Canadian Council on Child Welfare, 1931.

and child welfare have been, or are being conducted; others, such as the study discussed in this document, are in the early development stage. Other related Council studies have focussed on the day care of children, unmarried parents and their children, poverty (rural and urban), the Protestant Children's Village of Ottawa, employability, debt counselling of low-income families, homemakers, and family desertion.

A Review of the Literature

A number of studies on mental retardation have reported on the need for services by selected population groups, such as patients of hospitals or out-patient clinics. Only a few studies deal with the need for services by a total population of specified geographic areas. The available reports on studies of this nature demonstrate clearly the importance of accurate measurements, operational definitons, adequate statistical treatment of data, unbiased sampling, and the careful control of more important extraneous variables. Although comparisons of data from study to study are precarious at present there is evidence that the prevalence and types of mental retardation vary considerably from one area to another.

The study by Lewis[5] is a classic among incidence studies but is methodologically impossible to replicate. The study was conducted in six unnamed areas of England and Wales from

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5 Lewis, E.O., Report on an Investigation into the Incidence of Mental Deficiency in Six Areas, 1925-1927. London: H.M. Stationery Office, 1927.

1925 to 1927. The anonymity which Lewis maintained for the communities places a severe limitation on the usefulness of the data since little information is now available. It is known, however, that three areas were predominately rural and three predominately urban and that each included a population of approximately 100,000. Extensive definitions of mental retardation categories are included, but transposition to modern terminology is very difficult. Perhaps definitions used in the study are a function of the methodology, since inclusion of subjects depended upon a personal interview with one member - a medical doctor - of the research team.

Subject candidates were initially selected by teachers who were asked to name two or three children from each age (not class) group. Since it is known that some schools had relatively large mentally retarded populations the validity of the approach is open to challenge. Nonetheless, a group screening test was administered to the children identified by their teachers. The children were then interviewed for a final decision as to their acceptability as subjects. Interviewing began with the lowest scores and continued until a predetermined N for that locality had been reached.

Children under school-age were selected on the advice of the local Mental Deficiency Authority, welfare clinics, and other related agencies. Adult retardates were identified by Lewis through the 'key informant' method, that is, key community persons and social agencies were asked to identify possible subjects for study.

Bremer's[6] study of a population in northern Norway was carried out during the period of the German occupation. It is unusual due to the length of time involved and the intensity of individual observations on subjects. There are, however, a number of weaknesses inherent in the study which render the findings of relatively little value for purposes of comparison. The total village population was very small (1,325 persons), very isolated, and atypical in terms of North American society. The total study population included only 60 subjects of which 19 were members of the same family.

The research on Formosa by Lin[7] and that in Sweden by Book[8] seem to have a number of methodological similarities but both studies place the representativeness of findings in some doubt so far as incidence of mental retardation in the general population is concerned. Lin used local registers to gather extensive demographic data on all persons in the three study areas. Information was also available on suspected cases of mental retardation. Interviews were carried out with heads of families where mental retardation was suspected. Village elders

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6 Bremer, J. "A Social Psychiatric Investigation of a Small Community in Northern Norway". Acta Psychiat. Scand. Supplement 62, 1951.

7 Lin, T. "Study of the Incidence of Mental Disorders in Chinese and Other Cultures". Psychiatry, Vol. 16: 313-36.

8 Book, J.A. "A Genetic and Neuropsychiatric Investigation of a North-Swedish Population with Special Regard to Schizophrenia and Mental Deficiency". Acta Gent. Vol. 4: 1-100,1953.

and neighbours were also interviewed in an attempt to gather further information on known or suspected cases of mental retardation and to uncover leads to new instances. Diagnosis of cases was in terms of broad clinical categories such as schizophrenia and psychopathic personality. These terms are difficult to define operationally. Book identified his 97 cases from parish and institutional records, with inclusion in the sample based upon both clinical and social evaluations.

Essen-Moller's[9] study of a small Swedish exclusively rural population may be the most complete sample coverage of the major published reports. The researchers personally examined 98.8 per cent of persons listed on records of two parishes. The small sample may not be representative of the total 2,550 population of the two parishes nor of the larger rural population of the country. Classifications were, in terms of categories, inappropriate (i.e., subvalid, supervalid, etc.) for more modern empirical research.

Lemkau[10] and his colleagues in Baltimore also used a highly selective population of subjects. Records of social and medical agencies in one residential area of the city were searched for possible retardates. The researchers re-evaluated cases on the basis of criteria which has been established specifically for the study.

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9 Essen-Moller, "Individual Traits and Morbidity in a Swedish Rural Population". Acta Psychiat. Scand. Supplement 100, 1956.

10 Lemkau, P., Tretze, and M. Cooper. "Mental Hygiene Problems in a Urban District." Ment. Hyg., Vol. 25: 624-46, 1941; Vol. 26: 100-119, 1942.

The Onondaga County (New York) study may be the most criticized and least understood of modern studies on the incidence of mental retardation.[11] Nonetheless, it is also a valuable and influential contribution to the meagre literature on the subject, influential in terms of findings, since few rigorously controlled studies have been undertaken, and valuable for its exposition of methodological difficulties. The work was carried out within a specific frame of reference which was clearly stated by the authors. It is an analysis of prevalence, with reporting of cases by workers from various agencies throughout the City of Syracuse and Onondaga County. No subjects were personally interviewed or even seen by the research staff. Reporting was based on the following criteria: identification as definitely mentally retarded or suspected of mental retardation on the basis of developmental history; poor academic performance; I.Q. score, or poor social adaptation when compared with age peers.

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11 New York State Department of Mental Hygiene, Mental Health Research Unit. A Special Census of Suspected Referred Mental Retardation, Onondaga County, New York. Syracuse: University Press, 1955.

Goodman, Melvin B., Ernest M. Gruenberg, Joseph J. Downing, and Eugene Rogot. "A Prevalence Study of Mental Retardation in a Metropolitan Area". American Journal of Public Health, Vol. 46, Number 6, June 1956.

There were 3,789 children in the sample, representing a rate of 35.2 cases per 1,000 estimated urban, plus rural, population. A breakdown of rates shows 90 per 1,000 population for both races and sexes at age 13. For the non-white males the rate was 380 at age 11 and for non-white females the rate was 280 at age 12. The study was concerned only with the age group up to 18 years.

Prevalence rates from the Onondage Study are shown in Table I.

TABLE I

PREVALENCE RATES OF REPORTED MENTAL RETARDATION BY AGE GROUP, SEX, AND MALE/FEMALE RATIO: ONONDAGA COUNTY, N.Y., MARCH 1, 1953.

	Total		Male		Female		
	No. of cases	Rate	No. of Cases	Rate	No. of Cases	Rate	M/F Ratio
Total	3,789*	35.2	2,452	44.7	1,333	25.3	1.8
0-4	181	4.5	127	6.3	54	2.7	2.3
5-9	1,264	39.3	805	49.0	458	29.1	1.7
10-14	1,799	77.3	1,160	96.7	637	56.5	1.7
15-17	542	44.6	358	57.3	183	31.0	1.8

* Includes four cases with sex not stated and three cases of unknown age. From Goodman et al, page 705.

A meaningful comparison of findings for the studies reported is extremely difficult due to the methodological difficulties of many studies and the lack of transfer from study to study. This is further emphasized in Table II as reported by Goodman.

TABLE II

COMPARISON OF SELECTED AGE-SPECIFIC PREVALENCE RATES OF MENTAL RETARDATION IN THREE SURVEYS.*
(Rate per 1,000 Population)

	1 England & Wales 1929	2 Baltimore 1936	3 Onondaga County N.Y. 1953
0-4	1.2	0.7	4.6
5-9	15.5	11.8	39.3
10-14	26.5	43.6	76.9
15-19	10.8	30.2	44.5**

* Column 1 shows the rate per 1,000 of the population of defectives, based on Lewis's data. Column 2 of the table is based on the findings of Lemkau, Tretze, and Cooper who carried out a survey of mental health problems in the Eastern Health District, Baltimore, Md. Column 3 is based on the findings of the present survey. The age - specific prevalence rate for the age group 15-19 is used for the other studies, because of the absence of separate data on the age group, 15-17.

** Rate for age group, 15-17.
From Goodman et al, page 707.

The Delaware study may be the most outstanding attempt to date to carry out a closely controlled research study on the incidence of mental retardation. Jastak and MacPhee used the total population of Delaware as their universe.[12]

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12 Jastak, Joseph F., Halsey M. MacPhee, and Martin Whiteman. Mental Retardation: Its Incidence and Nature. Newark: University of Delaware Press, 1962.

The estimated population of 500,000 represented 109,489 households as defined by the United States Census. A sample of 2,325 households were chosen for study. This was later reduced to 1,442 households due to technical and other difficulties. One major instrument was employed for the study.

Findings of the study have not yet been fully published but available reports shows that the mentally retarded, as defined for the study, have fewer full-time jobs (32.7 to 45.9%) and that 60 per cent of the retardates' positions are in the three lowest occupational ratings - unskilled,service, and farm labour. The non-retarded constitute 15.9 per cent in these three categories combined. Seventy-four per cent of the retardates (in the 1950's) had incomes of less than $3,000 yearly against 52.6 per cent of the non-retarded. It is significant that of the retardates who were working some 84 per cent had had no special training for their jobs, while 48.9 per cent of the non-retarded had such training.

Almost 40 per cent (39.6) of the non-retarded received help in obtaining jobs while only 18 per cent of the retardates fell into the same category. Seventy-eight per cent of the retardates were reported to have found their own jobs. Sixty per cent of the reporting retardates left their last job because they were either fired or were dissatisfied with conditions, while 45.3 per cent of the non-retarded left their last job to obtain a better one.

A review of literature on the study of incidence in mental retardation reveals the remarkable inadequacies of most studies, the methodological difficulties, and above all, the potential for research in this area.

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APPENDIX A

POPULATION OF PRINCE EDWARD ISLAND BY COUNTIES, CITIES, TOWNS AND VILLAGES

COUNTY	POPULATION
KINGS	18,015
Towns:	
Georgetown	826
Montague	1,289
Souris	1,443
Villages:	
Cardigan	263
Morell	393
Murray Harbour	397
Murray River	522
St. Peters	289
PRINCE	42,688
Towns:	
Alberton	796
Borden	714
Kensington	1,022
Summerside	10,142
Villages:	
Kinkora	268
Miscouche	729
O'Leary	738
St. Eleanors	1,419
St. Louis	140
Tignish	982
Tyne Valley	149
Wellington	330
Wilmot	619
QUEENS	47,832
Cities:	
Charlottetown	18,427
Villages:	
Crapaud	239
Mount Stewart	429
North Rustico	874
Parkdale	2,071
Sherwood	2,407
Victoria	169
TOTAL POPULATION (Province)	108,535

From: 1966 Census of Canada Population, Catalogue No. 92-603, Vol.(1-3) May, 1967.

APPENDIX B

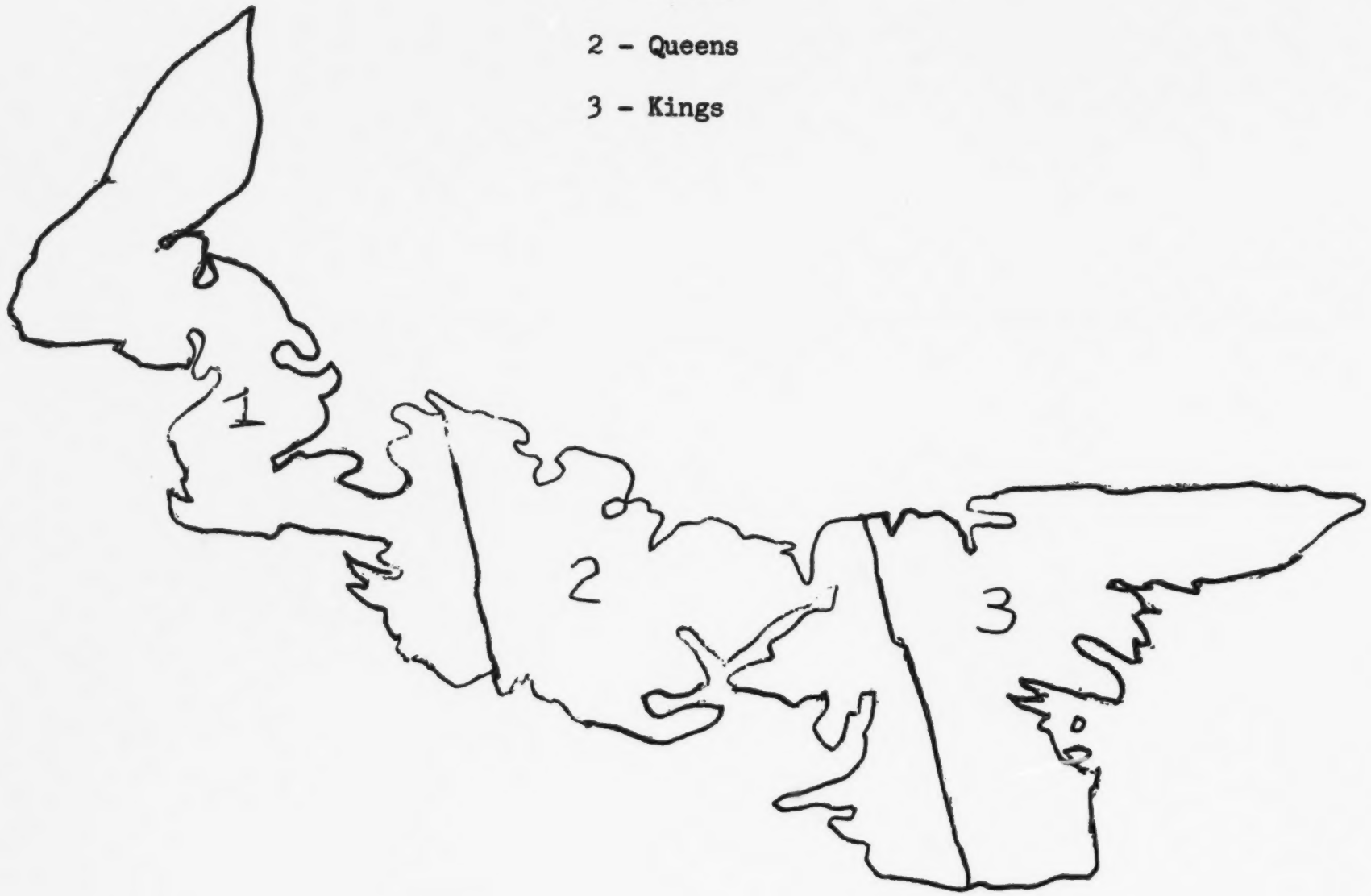
PRINCE EDWARD ISLAND

Counties

1 - Prince

2 - Queens

3 - Kings



Scale of Miles

0 5 10 15 20 25